

2010

Necessity of implementing electronic personal health information privacy regulation in Dominican Republic

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Necessity of Implementing Electronic Personal Health Information Privacy Regulation in Dominican Republic

By

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Thesis submitted in partial fulfilment of the requirements
for the degree of
Master of Science in
Networking and Systems Administration

**Rochester Institute of Technology
B. Thomas Golisano College
of
Computing and Information Sciences**

April 2010

Rochester Institute of Technology

**B. Thomas Golisano College
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Abstract

The use of technology has increased considerably in the Dominican Republic in the past years. All public and private organizations have started a process of digitize all information they manage. The health area is not away from this process and hence they have started to use personal health records in a digital format. However, the management given to this information is not regulated by any law in the DR. Doctors, medical centers, health assurance companies and patients treat this data as they want without any control which represents a huge privacy risk for patients in the country.

During our investigation we looked into Dominican law. For conducting this study we were advised by qualified attorneys in order to find a regulation regarding this topic. We conducted three interviews to lawyers where we asked them about their experience and existent legislation related to electronic PHR. According to the information we gathered, no regulation with this topic was encountered. Only several chapters referring to intrusions attacks and other about professional secret was found in the law. However, we did not locate any statement which strictly specifies procedures for electronic PHR information management.

We also interviewed three medical professionals and asked them some questions about the management of the electronic personal health records in the Dominican Republic. They talked about their experience and the different mechanisms for manipulating, archiving and disclosing information contained in the ePHR. According to their opinions, we found that every health care institution has their own security policy which is not supervised by the government which demonstrates the absence of a legal regulation in this area. We subsequently explained the importance of having a law which regulates information disclosure regarding this topic.

This paper also includes a suggestion about the topics that should be included in the electronic PHR regulation in the Dominican Republic. Health care centers, patients and health employees has their own responsibility in the management of this data which is presented in this research, as well as the type of information that is considered critical and hence should be protected by the regulation.

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1. Introduction:

In the past decade the Dominican Republic has been immersed in a digitizing process of all the information managed by the state. Civil Registry offices, migration departments, education among others public and private institutions have taken their information stored in papers and turned it to digital formats. Health area is not immune to these changes and for this reason medical centers and health personnel are also converting their information to digital. However, the process of digitizing the information needs to include the implementation of several policies to control the management of this new information. For this reason, controlling storage, transporting and disclosing processes have to be regulated by the government. In this sense we conducted a research to analyze the existence of regulations in this area of health information and the importance of having one.

1.1 Problem Statement:

Health information is considered as one of the most private information for anyone. Due to health care centers store digitalized patient's records information on servers and share them with other people through computer networks and since patients' health information privacy is critical, health care centers among other institutions who manage such information should administer it very carefully. However, this information should probably sometimes be helpful for the patient in some situations. For example, when someone has an accident and suffers many injuries it is very probable that his hurts prevent him from giving important health information to paramedics, nurses and doctors, so in this case the medical personnel can look for the patient's health record and be able to provide medical attention. Also if there is a crime situation, judges could need personal health records in order to clarify investigations and somehow the information must be disclosed. These are some of the reasons where we can find a personal health information regulation usable. This regulation could specify processes for disclosing patient's health information including the type of information that should be disclosed, people who is authorized to provide it as well as who is permitted to request the information. The regulation should also specify policies for data storing, i.e. where and how is the patient's

information going to be saved as well as who is in charge of storing the data and what backup procedures are going to be taken. Since personal health records are very critical information, the privacy and security needs to be guaranteed by the regulation as well.

In the Dominican Republic the law does not state any mandate that regulates the process of disclosing private health information. Health professionals such as doctors, nurses and bioanalysts manage such information as they see fit. Some of them treat the information as a professional secret; others follow the ethics and morality rules while others just disclose the patient's health information as they want which means that no legal mechanism currently controls the management of Personal Health Information.

In this research we evaluated Dominican Republic's law in order to verify if any regulation exists to guarantee the privacy of patient's health information and we found that some legal structures should be advisable in order to regulate this type of information exchange.

1.2 Motivation of the Study

In the Dominican Republic we hear of cases where patients complain about the way health care centers administers their records information. Many people complain because information about critical diseases they suffer from as well as personal contact information is disclosed carelessly. Also we have heard about cases where the hospitals and other centers frequently lose the patients records and analysis samples which causes a lot of problems.

1.3 Potential benefits of the study

A study related to this topic is important to every Dominican citizens and visitors because with the legal implementation of a private health information security regulation the government could guarantee that such data is going to be safe and that it will be disclosed only when and who it really needs to. The regulation will make healthcare centers implement security policies to protect digital data stored on servers and thus prevent unauthorized access.

1.4 Research Procedure

The methodology we utilized in this research was composed by five sections. The first part of our investigation consisted in studying the Dominican law in order to find legal statements regarding electronic personal health records. In this section we interviewed three attorneys with knowledge in this topic who responded several questions related to the Dominican legislation concerning this issue. We also made some research about how the medical centers treat the electronic health records. To accomplish this, we conducted three interviews to medical professionals with enough experience in public and private healthcare centers. We asked them about the procedures for requesting an electronic PHR, when the information can be disclosed and who can have access to them among others questions related to the problem we are trying to address.

After analyzing the reality in the ePHR information management and existent laws in the Dominican Republic, we mentioned several reasons why it is necessary to create a regulation which rules the management of electronic personal health records. In our research, we also gave some suggestions for implementing a regulation for ePHR. We mentioned the type of information that should be protected and the steps for certifying a medical center among other aspects that needs to be taken into account. Also, some steps that should be given when implementing the regulation as well as the creation of an institution that will be in charge of ruling electronic personal health records management were suggested in this paper.

2. Background

2.1 PHR Regulation Reference Models

The Dominican Republic is not the first country who will implement a regulation for managing information contained in digital personal health records. Several countries have created legal acts to protect this kind of information. One of the most well known regulations is the Health Insurance Portability and Account Act which is a legal document enacted by the United States Congress in 1996 [13]. This act consists in a group of rules created to protect health services in the country as well as to pursue the improvement of efficiency of health care systems and the continuity of health insurance coverage.

This federal law protects employees when they lose their jobs by guaranteeing their health insurance coverage. It also condemns the arbitrary exclusions because of health conditions and other patients' situation and at the same time promotes the use of saving accounts as a manner to afford future health problems [24].

One of the most interesting parts of this regulation is the Administrative Simplification subtitle, whose purpose is among other things, to promote the creation of a health information system where patients' critical data can be managed electronically. The act rules transactions mechanisms as well as standardized processes and protocols to guarantee security and privacy of health data [23] [14] [10].

European countries have also been using electronic Personal Health Records several years ago. Regarding protecting information privacy they use an omnibus approach which specifies rules not only for securing health information but also all personal data. Their method controls mechanisms for exchanging information all around the European Union. However, European countries started concerning about the reasons why electronic health records were not more widely used in the continent, so in 1996 they decided to create a network of organizations called ProRec which is in charge of analyzing the limitations and obstacles that prevent a widely electronic personal health records implementation [25]. As a response of ProRec was created the European Institute for Health Records which consists in a group of non-profit organizations that promotes the use of high quality electronic health records information systems. This institute is composed by 15 ProRec centers in Europe and is in charge of observing health records information systems who want to acquire European Union's certification. This certification includes quality and validation of clinical prototypes. [25]

2.2 Philosophy of Protecting Personal Health Records

2.2.1 Fair Information Practice Principles

In the past years governments in the United States, Canada and Europe conducted a study about what are the most important things that need to be taken into account when protecting personal information [26]. Their study showed as a result that there are five core principles for guaranteeing privacy protection. The first principle is the Notice/Awareness which states that

every person should be informed before any institution collects or discloses personal information. This is considered the most relevant principle for information privacy because without prior notice the organization should not be able to disclose any personal information. According to the study the most important things that tell us that a good awareness have been addressed are the identification of the institution who is gathering the information, what the data is going to be used for and the identification of possible recipients. Also, the consumer should be informed about the information is required or voluntary as well as the steps that the collector will take in order to ensure confidentiality, integrity and quality of the data [26].

Other of the principles mentioned in the report is the Choice/Consent. This specifies that any action to be taken regarding personal information should count with the prior person's approval. Also, the Access/Participation principle is considered as one of the most important in this philosophy. This states that the owner of the information should be able to access data related to him or her [26].

Integrity/Security is the fourth principle found as important according the mentioned study. This principle aims to guarantee that institutions address mechanisms that assure the data will remain secure. Finally, the Enforcement principle is the one which states that any violation of the principles cited above will be punished by legal regulations. [26]

2.2.2 Organizational Policies for Protecting Electronic Health Information

When we are going to design a regulation to protect electronic health records we have to think not only about technical issues but also administrative decisions because they are going to establish policies that we will subsequently try to address with technical solutions. These policies should make a balance between the necessity of accessing critical personal health information and the citizens' rights for maintaining privacy.

The Committee on Maintaining Privacy and Security in Health Care Applications of the National Information Infrastructure, Commission on Physical Sciences, Mathematics, and Applications and National Research Council in their book called "For The Record, Protecting Electronic Health Information", [27] state that one of the most common policies that should be included in any regulation is the security policy. This can describe the methods the system will use to authenticate the users as well as access control. This policy should also be based on a risk assessment analysis which should include the possible threats and values of the assessments protected. The security policy necessarily has to work in conjunction with a confidentiality policy in order to provide a correct method for accessing the data while maintaining it confidential.

Other policy that health care organizations usually include is the policy for protecting sensitive information. There is some health information that needs a special treatment because of its sensitiveness. Information such as HIV disease, drugs cases and others are examples of critical information that institutions protects with a higher level of criticality [27].

Researchers are accustomed to access patients' health information for their investigations. For this reason health care organizations have policies on research uses which specify that the intended use of this data should be established previously. Their policies also state that the identification data should be removed from electronic and paper records as well [27].

Many other policies are being implemented in health care organizations in order to protect personal health records. However, we think that at this level we have a clearer idea about how to protect patients' critical information contained in electronic records.

3. Related Work

Many other researches have been done around this topic. However, the two main points to analyze regarding this idea are the data security fact as well as the user access to the health records.

3.1 Security Warranty in PHR Data Exchange

Undoubtedly security is the main concern when we talk about Personal Health Records. People worry about who will be able to access their private information. In this regard I agree with an article published by LiGuo Huang, Xu Bai and Suku Nair where they explain how they realized that working in a patient-centered environment brings a lot of security breaches that need to be addressed [2]. They state that the information security and privacy could not only be guaranteed by using just technologies but with the implementation of a process which helps to evaluate a set of metrics to assess security risks for health-care systems.

They found that HIPAA regulations focus more on administrative security controls. However, they believe that other security policies should be implemented on patient-centered systems in order to provide security and data privacy. Also they concluded that authorities should identify emerging security risks and thus implement mechanisms to verify security on a health care system. The process suggested by investigators could be changed and adapted to any health care system in order to comply with regulations such as HIPAA [2].

Also governments have been making big efforts to strengthen national security of countries. Such is the case of the United States of America which according to a paper published by Swire and Lauren Steinfeld, found several issues regarding information security [6]. They cite specific cases from the terrorist attacks the United States were victims of the September 11th of 2001. They say that after these attacks the US government incremented security mechanisms to guarantee national security. The president Bush proposed the USA- Patriot Act to mitigate national security risks. Also the president Clinton had previously proposed updating the same law to increase the information privacy in the US.

In their explanation they state how useful could have been the HIPAA regulation which could make medical personnel to report any strange issue in a medical center regarding any terrorist.

They also mention the ANTRAX attacks from fall 2001 where a good information disclosure regulation could be useful to alert all citizens about mechanisms to prevent attacks.

We believe that this report explains with real examples how necessary is a law to regulate the disclosure of private information especially health records data. The Dominican government, as well as other government of the world, has been implementing many security rules in order to improve national security. In my opinion the citizens' private information could be a target of attacks for terrorists hackers, so since the personal health information records is part of the individual privacy of citizens, it needed to be well protected in the regulation we proposed.

In the Dominican Republic one common issue we find is that many of the laws were created decades ago and most of them are not applicable to modern times anymore. That is because many of them were designed to solve problems that were present in that time, but they do not exist today. So, what we state is that the regulation we create to rule electronic PHR should be constantly revised in order to make the appropriate modifications at the right moment. Our idea agrees with a research made by Jinx P. Walton where he analyzed the situation of the University of Pittsburg where when building a collaborative network community the new applications designed should guarantee that the critical information should not be disclosed carelessly [3]. He mentions that HIPAA, the USA-Patriot-Act among others regulations implemented lately have had a lot of impact in information security. For instance, the HIPAA is a regulation which protects confidential health care information by using a series of security standards in order to guarantee privacy. Other regulation studied by the researcher is the Government Information Security Reform Act (GISRA) which is a legal rule that uses a framework developed to maintain information security in federal agencies and ministries among other institutions that manages government information. The third regulation cited by Walton is the Economic Espionage Act (EEA). This document penalizes downloading, exchanging and storing trade secret information without previous permission. Taking into account the purpose for what all this acts where designed, the researcher proposed a University-wide security plan which will address security within the system. This plan shall include policies, business practice changes and user awareness concerns [3].

Walton concluded that the plan he developed should have a lifecycle in order to be effective in the long term. He states that the plan should include a constant security architecture reassessment where new security breaches could be discovered and thus the required modifications are added to the plan [3]. I think that this is because since technology changes very quickly nowadays, it becomes necessary that every regulation created to control the information privacy management be adapted to current mechanism. For example, if we create some security policies for protecting some important data we probably thought about the regulation according to today's security risks. However, it is very probable that in a few years other security vulnerabilities will be found on systems and our old regulation will not be able to mitigate them.

The papers mentioned above explain several reasons why the implementation of a regulation for Personal Health Records data exchange is strictly necessary. The researches make evidence of the importance of guaranteeing data privacy. However, the privacy should not only be maintained by administrative mechanisms but also technical aspects should also be taken into account.

In order to guarantee data integrity and confidentiality one of the most common technical mechanisms utilized by systems is the data encryption. This topic was subject of a research made by Schadow, Shaun J. Grannis and Clement J. McDonald where they specify privacy methods for preserving data in a clinical research network [4]. For this work they proposed a cryptographic method using a strong keyed-hash algorithm. They pretend that the critical information that travels through the research network keep encrypted in order to maintain its privacy. They also utilized likelihood ratios to measure the privacy and they found that using a deterministic matching takes to a higher privacy risk than rules based on a single identifier vector.

The researchers suggested a mechanism where they use a reduced keyed hash which passes through a mathematical filter. This encryption method could be well applied to health care information records in which the patients, according to the researchers, could only be identified by the demographic data [4].

The algorithm suggested by Schadow, Grannis and McDonald [4] seems to be very interesting and useful and can be applicable to the regulation we are suggesting. We perfectly agree that the data exchange should pass through an encryption system in order to guarantee security.

However, it is strictly necessary that only one encryption method should be used in the whole system to prevent compatibility issues, hence we should use a standardized encryption mechanism and protocol well known in information technology industry. For this reason I do not think that the encryption method showed by the researchers mentioned above is a good encryption option for implementing in the Personal Health Record electronic system.

When protecting personal health record data encryption is not enough to maintain security. Storage and disclosure procedures should also be regulated by the legislation. I agree that the regulation needs to contain policies for disclosing information in PHRs, but we need to make those disclosure restrictions technically possible. Regarding this topic we found a research made by David Bauer, Douglas Blough and Apurva Mohan [28] where they explain that the amount of personal information stored in electronic health records is very much. You can have information such as address, names, social security number, and date of birth among other basic data.

However, not all the information contained in the electronic Personal Health Record is basic. In the PHR you can also find information such as credit card numbers as well as financial records and other information that the patient may not necessarily want disclose to everyone who has access to the PHR.

For this reason the researchers proposed a mechanism where users have more control over their personal information. They planned to do so by using the principle of “least disclosure” which states that the user should give the provider only the necessary information needed for the work it is going to make. They found a method to use a redactable digital signature which could be modified by the user who could add to the signature only the information he wants to disclose [28]. This method differs from the “all or nothing” principle which states that if the provider has access to the electronic PHR he could visualize all the information contained on it. However, with the new mechanism suggested by Bauer, Blough and Mohan [28] the user will have flexibility to provide some data while hiding other that he considers critical maintaining the cryptographic check process of each digital data.

According to this research the information will be divided in individual elements of personal information which is called a claim. The redactable signature will be modified by the user in order to permit access to only some of the claims in the record such as X-ray images, studies results and other medical processes.

I found this idea very interesting because the “all or nothing” principle is very limited for the system we want to build. I think that the patient should have the flexibility for deciding which information to disclose to specific health personnel. The use of a digital signature is a very viable way to protect private information.

3.2 PHR Information Access

The other point of concern when designing an electronic PHR regulation is the information access. The procedures for requesting information contained in PHRs need to be specified in the regulation. During our investigations we found two ideas about the information access. The first point states that the patients’ information should be managed from shared network perspective where all components of the medical services system can have access to, i.e. doctors, nurses and medical centers among other institutions can create and modify health information through the network. An example of this approach is found in an article published by Gunther Schadow, Shaun J. Grannis and Clement J. McDonald who conducted an investigation where they plan to build a nation wide biomedical research network where scientists could share information about patients that are in databases and thus use this information to develop projects such as medicines, diagnostics among others discoveries [4]. However, since this is patient’s health records information it is strictly necessary to guarantee its privacy.

The other idea found was that patients could carry all their information in portable devices and thus access such information whenever needed. Regarding this topic Wai Gen Yee and Bret Trockman [1] made some research where they state that healthcare centers should have a system which could deliver such critical information about a patient in a favorable time.

In this work they proposed a personalized healthcare information system where patients could carry all information needed [1]. They proposed such system that comply with HIPAA specifications and where the integrity and authenticity of the data is guaranteed.

The PHR system that the researchers proposed include several features such as portability which enables the patient to carry an executable software and data files which users could have stored on any mobile device. Other feature is the Multi-user access through which patients, pharmacists, doctors, and nurses among other health professionals will be able to add records to the patients' PHR. The record verifiability is another feature that permits to verify the records' authenticity. Other very important characteristic of the system proposed by the researchers is its compliance with HIPAA. With this feature the system permits the users to access the records under HIPAA compliant ways, i.e. the PHR access will be strictly secured.

I think the idea of having a portable device where patients could carry their PHRs is very interesting especially when you think about having a mobile network composed by all patients' devices. This topic was treated in a research made by Michelle Watson where she focused on guaranteeing privacy when managing this kind of information through Mobile Ad-hoc Networks (MANET) [29].

According to Michelle's study the mobile network may work in three modes. The first mode is called Stand Alone Mode and represents the type of operation of a device when is not connected to any network. Other operation mode cited by Watson is the Huddle Mode where devices are connected in a peer to peer environment such as Blue-Tooth. The third of the proposed mode is the Roaming Mode where devices connect to a cluster. In her study she explains that the device's mode of operation rules the flow of the data within the network.

One of the example cases where this system could be useful is in cancer diagnosing. Watson states that once a patient visits a physician he could consult a cancer specialist to address the case. This consult could be done by sending the Personal Health Record of the patient to the oncologist through a roaming network. The oncologist will address the pertinent studies and will include results in the patient's record which could be accessed again by the physician. In this

case the healthcare practitioners are responsible for ensuring that the records of an individual remain secure.

The system proposed by Michelle Watson could be also used on hemodialysis treatment. What she states is that a patient could manage its own hemodialysis process and take the information home. The patient could go to another hospital and give the nurse or the doctor all the information regarding the previous sessions by exchanging information logs obtained from the machine results.

I think that both methods of accessing the PHR information are very applicable in a system like the one we are suggesting. We propose to have a national medical network where medical centers and other institutions could access patients' personal health records and modify them depending on the needs. However, we think that patients' should also carry their information on mobile devices. Whenever their records are modified they will connect to the network and update the information on their personal device. Medical centers and patients will also be able to access the information by using some kind of web application where they can visualize all the data contained in PHRs. An example of an efficient web application was presented by Francisco Romero, Jesus Serrano Guerrero and Jose Olivas who conducted a study where they analyzed the use of a tool to improve the data retrieval and filtering when managing Personal Health Record information [30]. They realized that due to the expansion of the Internet new commercial applications have been released by important companies such as Google and Microsoft. However, they state that this huge amount of information available through a web application needs to be organized in order to provide a more efficient service to the users.

According to their research most of the web applications that work with Personal Health Records use a standard development method using XML as the language which assures that the information could be easily read and processed by any application. Some of the most popular applications use a standard called Continuity Care Record for displaying the record summary, but they state that the mechanism could be improved in the retrieval and filtering section of the applications.

The researchers developed an application called Bucefalo [30] which is web-based software for PHR management. This appliance provides a web interface to display the information from the database. Bucefalo makes the work in two steps. The first one is the search step where the application processes the abbreviation entered by the user and compare it from a list previously entered in the system. Then they use a Semantic Query Expansion function which uses synonyms and phrases to help complement the one entered by the user as well as the use of multilingual for finding equivalent meanings when the information entered is in another language.

With an application like this patients and medical institutions will be able to access their information from every where through the Internet.

4. Methodology and Obtained Results

4.1 Study the Dominican Republic's Law

In this section of the research, since we have no expertise in law issues, we obtained the opinion of three attorneys in order to gather information about the Dominican law. We asked them if there is any regulation for protecting the electronic PHR privacy. For electing our respondents we verified their background and we made sure they have prior experience in aspects related to health cases as well as technological issues. We decided to interview legal advisers from the two most important health care centers in the north region of the country, Hospital Metropolitano de Santiago and Clínica Corominas, because they have a qualified experience which could help us in our purpose.

The first lawyer we interviewed was Dr. Daisy Taveras who is the legal consultant of Clínica Corominas which is one of the most important medical centers in Santiago. Dr. Taveras has a Masters Degree in Labor Rights and Public Administration. She is specialized in social security, civil rights among others topics. She has a PhD in Education from the UNED of Costa Rica. Dr. Taveras answered our questions at her office in the Clínica Corominas in an interview for about one hour. According to Dr. Taveras's interview¹ she thinks that the Dominican Republic does

¹ See Appendix A

not need a regulation for protecting health records because the General Health law regulates the disclosure of this information. She cited some examples of cases she has experienced which are detailed in the complete interview presented in the Appendix A of this paper.

The second interview we conducted was to Lic. Rafael Armando Vallejo who is a lawyer with more than 30 years of professional experience in the legal area and serves as the legal advisor of the Hospital Metropolitano de Santiago (HOMS) which is the largest and modern medical center in the north region and one of the most important in the country. Our interview lasted one and a half hour and was made at his personal office located in Santiago. During our interview Lic Vallejo explained that there is a clear need of a regulation in this regard especially in these times where the automation of health administrative tasks is in constant progress. In the Appendix A we included the complete interview we conducted to Lic. Vallejo where he speaks about examples he has experienced among others topics.

The last attorney we interviewed was Lic Dariel Suarez who is the Student Dean of PUCMM. Lic Suarez has a Masters Degree in Telecommunications Rights from the Carlos III University of Madrid, Spain. We chose Lic Suarez as a respondent not only because of his expertise in telecommunications rights but also because as a young professional is up to date with the latest techniques in this regards. We interviewed Lic Suarez at his office in the PUCMM for about one hour and during our conversation he explained how the new constitution of the Dominican Republic law, which was enacted in January of this year, includes some articles related to privacy protection. He mentioned the 44th article about privacy rights and personal honor which states that every person has the right of accessing the information contained in public or private registries as well as knowing what the information is going to be used for [37]. He cited also the 70th article [37] of the constitution about Habeas Data which states the right of every citizen of proceeding in judicial actions for accessing information related to him in public and private registries.

From our interviews and subsequent investigation of the law we found that in the Dominican Republic the only law related to electronic issues is the law 53-07 about high technologies crimes [20]. This law contains several articles to control all transactions and topics related to technology. Issues related to telephone and internet service providers, unauthorized access to

software, damages to databases, computer malware propagation among other technological crimes are punished by this law. The following paragraph was taken from the “Law Number 53-07 about High-Tech Crimes” text in order to understand the purpose of this legislation:

“Article 1.- Law Objective. This law aims at comprehensive protection of the systems using information and communication technologies and content, as well as the prevention and punishment of crimes committed against them or any of its components or committed using such technologies to the detriment of physical or moral persons, as provided in this Act. The integrity of the information systems and their components, information or data that are stored or transmitted through them, transactions and commercial agreements or any other type of crime committed through them and the confidentiality of these documents are all real legal protection.”[20]

In the same law we found many articles which aim to protecting information systems technologies. For instance, we could find that the 19th article talks about the use of equipment for privacy invasion which punishes the illegal use of electronic software and any device which harms any type of privacy applying punishments up to two years of prison and up to 500 the minimum wage.[20] In addition, the 10th article of the same law sanctions the damage and illegal data modification, i.e. erasing, editing, copying and altering data and components of electronic systems and software for fraudulent purposes. These actions could result in a sentence of three to twelve years and a 500 minimum wage fine. [20]

In our research we also studied the Dominican Republic’s penal code [7]. In this part of the law we couldn’t find any specific statement that refers to electronic PHR privacy. Despite this, we found that the second paragraph talks about libel, slander and secret disclosure. Specifically the 377th article states that doctors, nurses, surgeons and all personnel who is depository of someone’s secret and who disclose this information without permission should be punished one to six months of prison and a fine that could vary from ten to one hundred pesos.[7]

Other laws studied in this research was the number 42-01 also named the Health General Law which in its 155th article states that medical centers must have archives of health records from every patient that attend the hospital. Also as mentioned before the 44th and 70th articles of the

constitution speak about the rights Dominican citizens have of accessing their information contained in registries as well as knowing what destiny they will take.

From all this investigation we can say that although we could find several articles partially related to our research topic, they all specifies punishments for offenders and maybe prevention mechanisms, but no rules are dictated to guide patients and medical personnel in giving the health records a secure and adequate management. The information presented above is a clear sample of that Dominican law lacks of a specific regulation which controls the management of electronic personal health information.

4.2 Current electronic PHR management in Dominican Republic's medical centers

In this section we contacted three professionals from public and private medical centers in the Dominican Republic in order to gather information about the management of electronic personal health records.² The first fact that we found is that in Santiago, D.R. just one medical center manages its patient's health records 100% electronically. The rest of the centers keep personal health records on hard copies archived physically. Although no specific regulation for protecting electronic PHR exists in the Dominican Republic, some healthcare centers have adopted an internal procedure which rules the management of such records, but just as companies' security policies and which could vary from one center to another.

The methodology for selecting our respondent we thought convenient electing a doctor that was strictly related to administrative labors in a health care center in order to obtain his opinion from an administration perspective. We also thought about interviewing a doctor who has enough field experience in private medical centers. We thought that he could help us to visualize the topic as a field professional in private practice. Finally, we considered obtaining an opinion from a doctor who works for a public hospital in order to understand how is the process managed in government's hospitals.

² See Appendix A in Appendices section

One of the most interesting interviews that I could make was to the Hospital Metropolitano de Santiago (HOMS) medical director Dr. Santiago Garcia who is also one of the most notable cardiologists in the north region of the country. The HOMS is the most modern and important medical center in the north region and one of the largest in the whole country. Dr. Garcia received us in his office at the HOMS and answered our questions for one and a half hour. During the interview he explained how they manage digital patient's information. In the method they use, every patient who wants to receive a copy of his personal health record needs to ask his doctor for permission and the doctor should make the formal request to the Medical Direction Department of the center who will subsequently provide the information to the patient in papers or digitalized on a CD. This process could take several minutes and it has no cost. In this center the records are stored permanently on various server farms here in the Dominican Republic and in Alabama in the United States of America and could only be accessed in person by the patient or by the parents in case of an underage patient. If the patient is an adult, the record could only be accessed by another person with previous authorization or by a direct relative in case that the patient is not in mental capabilities to give consent. Also the information on the record could be disclosed every time that it is required by a legal document such as a sentence of a judge or if it is requested by the government's health ministry.

In the HOMS, all the PHR work is done through specialized software called "TELVENT". By using this software all personnel who have worked with a patient have granted access to modify information about the patient, i.e. doctors, nurses and others can include diagnostics, prescriptions, and surgery information among other interesting data related to the patient. However, each kind of professional has a different level of access which means that doctors could only modify one part of the record related to doctors, nurses can vary just the part that is under their responsibility and so on and thus every modification to the record is registered as an event in the software which could be audited later. Only the CIO of the company, the Medical Director and the CTO have full privilege for consulting and modifying any record.

We also interviewed Dr. Miguel Antonio Molina Cruz who is the president of the Orthopedic Dominican Society in the north region and who is an orthopedics professional with more than 30

years of experience.³ Dr. Molina works in Clinica Corominas which is one of the most important private medical centers in Santiago, D.R. and in Jose Maria Cabral y Baez Regional Hospital which is a government's hospital where also doctors can take courses to obtain masters degree and specialties. He also serves in other medical centers in San Francisco de Macoris as an independent professional. For interviewing Dr. Molina we had to visit him at his house where we had dinner and talked for about two hours about the questions we had regarding electronic personal health records.

According to Dr. Molina's experience no general regulation exists to manage the personal health records in medical centers in the Dominican Republic. In Clinica Corominas patients' records are stored physically in papers and archived so.⁴ This medical center uses information systems, but only for administrative purposes. They enter information about the patient such as names and diagnostics as well as the amount of money the patient have to pay for all medical procedures he has been through. However, the system is not used for health information such as prescriptions, surgery procedures among other critical information that should be on a record. Such information is stored in physical records where doctors, nurses, physicians and others have to write down relevant information⁵. Besides, no strict procedure exists for requesting patients' health records or exchanging such information. If a patient wants to obtain his record it is necessary to contact the medical center's administrator in order to know steps for obtaining it.

Similar cases can be found in public hospitals where no digital records are used. According to Dr. Ramoli Mena who is a general doctor and is coursing the orthopedic specialty in Hospital Dario Contreras in Santo Domingo, the hospital does not use a standardized method for managing patients' health information. We visited Dr. Mena at his office in the hospital where we talked for about one hour and he commented us that in the last months the government has been implementing a project which consists in installing an information system where all

³ See Appendix A in Appendices section

⁴ See Appendix C in Appendices section

⁵ See Appendix C in Appendices Section

patients' health information and other data will be stored on it. With this project the government intends to migrate all physical personal health records to a digital format.

Although, the interviewed medical centers have a methodology to manage the digital patients' information, it is not obligatory to have such internal regulation. That is why we could verify according to the people's interviewed testimony that the Dominican Republic lacks of a law which regulates issues related to PHR. The law neither states any sanction to people who violates patient's privacy regarding the PHR as well as no special training is given to the personnel in charge of management of this critical data. The way that the medical centers usually prevent that personnel illegally disclose patient's information is by forcing them to sign a confidentiality contract where doctors, nurses and other professionals undertake not to divulge any type of information from the patients without a prior authorization.⁶ Other legal document used to guarantee is the Code of Medical Ethics of the Dominican Medical Association which was enacted by President Leonel Fernandez in the decree number 641-05. The fourth article of this code states that: "Is an obligation of the doctor to maintain a professional secret a must that last for ever even when ceases providing medical services, except in cases specified by the law" [36].

4.3 Importance of Electronic Personal Health Information Privacy Regulation

Privacy is one of the most critical rights that citizens from all world claim. It is so important that it is granted in the United Nations Covenant on Civil and Political Rights. The article number 17 specifies that "No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honor and reputation." [21].

Another example of the importance of personal information privacy is stated by the European Commission's Joint Research Centre (JRC) which conducted a study on "Security and Privacy for the Citizen in the Post-September 11 Digital Age: A Prospective Overview" which was commissioned by the European Parliament [22]. This study showed as a result that after the September 11 terrorist attacks many governments have gain more control over their citizens' private life. They have implemented technologies for identity management; location-based

⁶ See Appendix B in Appendices section

services among others mechanisms which compromise the citizens' privacy. The report offered by the European Commission states that there is a need of maintain a balance between securing citizens data and maintaining its privacy [22]. This concern is also applied to citizens' health information because revealing information about themselves could harm people not only physically but also psychologically. We can cite several cases in order to demonstrate how harmful could be a mistake on private health information disclosure. For example, a famous tennis player's positive HIV positive condition was divulge by an employee of a medical center and this was published later in a newspaper without previous permission [16]. Other important people have been victims of irresponsible healthcare workers who sold their personal health records. These are some of the thousands of cases of PHR privacy violations around the world.

Since the Dominican Republic lacks of a public regulation in this regard it becomes necessary to implement a law which guarantees PHI privacy. This policy will limit the use and disclosures of critical health data establishing security parameters for all personnel linked to healthcare and thus ensure patients' privacy.

It is usually seen that workers are fired from their jobs or rejected from giving them a new one because the contractors find out that the employee suffers from any disease. Other people are denied from acquiring health insurance just because the person has some affliction. In addition, it is a common practice that advertising agencies obtain information about medicines that patients consume and in that sense elaborate annoying campaigns directed to those people. Besides all these examples and this is the focus of this research, technological issues need to be addressed in a privacy regulation for health information. Since the PHR digitalization is becoming popular in the Dominican Republic, the public regulation should control the way this critical data is accessed, transported and stored and thus establish penalties for people who violates the rules.

However, the public regulation for protecting electronic PHR privacy could not only be applied to medical centers and health insurance companies but to other companies who offer services related to health. For example, the regulation could also address policies for pharmacies, medical transcriptionists [15], and medical contact centers [33] among others medical institutions.

4.4 PHI Management Regulation Topics

In this section of our research we gathered information about what topics should be included in the PHR regulation in the Dominican Republic. Information disclosure regulations and type of information that should be protected are part of the topics that we found interesting to be included in the new regulation. In this section we briefly describe such topics.

4.4.1 Disclosure Policies

The government should build a set of policies which rule the correct disclosure of patient's information process. According to [31]] the following is a list of information that should be considered as confidential:

- Responsibilities about the PHR information, i.e. doctors, health care centers, health assurance companies, patients
- The process for requesting a record
- Type of copies, i.e. hard copies or soft copies
- Cost of the process
- Period of time the process should take
- Who can access the PHR?
- How and who disclose adults and underage patients' records to?
- PHR disclosure to the government Public Health Ministry
- PHR disclosure when a justice request is present
- Specify training certifications for personnel who will work with PHR
- The regulation should specify the penalties for violators

4.4.2 PHR and the Patients

Patients should be a really important part of the regulation and hence should have duties and rights within it. These should include:

- Patients should have control of their health information
- Patients should be asked before any disclosure records

- Patients PHR should receive guarantees of protection and privacy in any institution related to health.
- Patients should have the rights of suing any health institution or employee who violates the regulation

4.4.3 PHR and Health Care Organizations

Other important parts in the regulation are topics related to health care institutions. The regulation should include standards to rule the role of these organizations. According to [35] the health care centers have the obligation of:

- Ensure the availability, integrity and confidentiality of the PHR
- They should have mechanisms to prevent attacks or to recover after one.
- The storage of the information should be accomplished by having site and equipment redundancy.
- The transport of the data should be encrypted.
- They should guarantee the patient that a PHR request should be served as stated in the regulation.
- They should guarantee that the personnel who work with PHR has the proper training and experience.

4.4.4 Information that should be protected

The regulations should mention what type of information is considered critical and hence should be protected. According to [34] the following is a list of information that should be considered as confidential:

- Names
- Addresses
- Telephone numbers
- E-mail addresses and any electronic account
- Electronic addresses such as URL, IP addresses
- Bank accounts
- Legal ID number

- Legal Status
- Family names
- Employment information
- Financial information
- Medical record numbers
- Medical proceedings such as surgeries, consults, treatments, medicines
- Dates
- Properties numbers, i.e. house, buildings, cars, etc.
- Biometric data

4.4.5 Process for Implementing the Regulation

In order to implement the regulation several tasks need to be done previously. First the Dominican government has to create a commission composed by notable personalities from different social entities who will guide the implementation process. I like the idea of creating a specialized institution such as the European Institute for Electronic Health Records (EuroRec) [25], who will be in charge of observing and certifying any health care organization or individual person that wants to achieve the certification for operating within the system. The institution could be named the Dominican Institute for Electronic Health Record (DIEHRec) and initially should be composed by members from different existing Dominican institutions which have some relationship with the health area. For instance, it should have members from the Ministry of Health who will give advises regarding medical treatment and procedures. The institute should also have members from the Dominican Institute for Telecommunications. These technology specialists will be very valuable when technical issues need to be addressed. Health care assurance companies and medical centers should be represented in the DIEHRec as well. Moreover common citizens should be represented by any of the workers unions that functions in the country. This way all interested parts will have representations within the organization in charge of creating the certification requisites and implementation of the regulation. The created institute will have to constantly monitor the behaviour of certified organizations in order to find any irregularities in the processes related to electronic PHR.

In order to obtaining the DIEHRec certification health organizations have to write a communication as an evaluation request. The DIEHRec inspectors will then go the organizations' offices and thus run the certification tests. During the certification the organizations' Chief Medical Officer (CMO) as well as the Chief Technology Officer (CTO) needs to be present in order to explain all internal and external processes related to electronic health records. The CMO should talk about the administrative and medical mechanisms used in the center and the CTO will present the information system and technological methods used such as encryption mechanisms as well as other policies to guarantee data security. The DIEHRec should also certify personnel who will work directly with electronic personal health records, i.e. doctors, nurses, physicians and pharmacists among others professionals should comply with the regulations. This could be achieved by offering the personnel different types of trainings which will give them a better comprehension of the regulation.

If the evaluated health organization passes the test the DIEHRec will issue a certification document specifying that this center complies with the Electronic Health Records regulation. The organization has to recertify the system every three years in order to guarantee that it complies with the latest best practices established internationally.

Regarding individuals the Dominican government will start an advertising campaign informing all citizens that they have to provide all their personal information to the national health information network in order to be kept in the database for future access. This campaign will last at least one year which is a reasonable time for everyone getting into the system. Also, medical centers should enter newborns information to the system. For that reason it is obligatory for all health centers to be certified by the DIEHRec and the lack of this guarantee will be object of penalties.

5. Conclusion

The use of electronic data has become very popular in the Dominican Republic during the last decade and the health information digitizing process is growing considerably. However, since the use of Personal Health Records is a new practice in the DR the management of this information represents a problem for patients' privacy. This problem could be solved by implementing a personal digital health record information privacy regulation in the Dominican Republic which was the solution we presented in this research.

The Dominican government should include in the law a regulation that rule the correct management of electronic PHR. A good idea is to evaluate other regulations that exist in other countries which could be used as a reference for Dominican PHR regulations. For instance, the Health Insurance Portability and Accountability Act (HIPAA) is a very complete legislation created in the United States of America and that could guide the Dominican government to design theirs. The DR could also refer to the European Institute for Health Records (EuroRec) which is a non-profit organization for observing the procedures related to electronic health records in the European Union.

The regulation we suggested should have disclosure policies which controls the way the electronic PHR information is disclosed. The regulation should state the methods for requesting such personal information and the rights and obligations of every part involved in the process. It should also set a group of rules for health care centers in order to control the management they give to the digital data. These rules should include the transport methods that the system components will utilize for exchanging data. This includes transport protocols, network media and technologies as well as encryption algorithms that will guarantee data confidentiality and integrity. The storage process should also be taken into account. The data will be stored in different server farms so we can have hardware and site redundancy providing us a high availability network design. The regulation will also include a disaster recovery plan. This plan will include periodical backup procedures, alternative sites and online data replication so we can recover from any disaster affecting the system the less possible.

Besides the healthcare centers the regulations should also integrate patients to the process. The regulation we proposed states that patients should have control of their digital PHR information and that they should authorize any disclosure of the data except when judicial purposes request it. The patients' data that should be protected are names, physical and electronic addresses, bank accounts and any other personal information that could be considered as confidential.

Other of our suggestions is that the regulation the congress come up with should be revised at least every three years. We strictly recommend this because the information technology world is constantly changing and in the same manner hackers and intruders improve their skills and develop new mechanisms for violating relevant data. So, the congress should also constantly be advised by information security risks professionals about the latest security breaches as well as their mitigating methods and thus adapt the regulation to the newest health information violation prevention.

6. Future Work

Regarding this topic, the completion of this work will be reached by the elaboration of the regulation. In order to accomplish this task the Dominican Republic Congress in conjunction with technology information experts, should debate all topics mentioned in this research and come up with a final document that should be approved by them and subsequently enacted by the president of the country. Once the regulation is implemented all participants in health area should start applying it in order to improve the management given to electronic PHR.

The regulation that the congress will release could be complemented with many features. One of the works that could be done regarding the regulations is the implementation of electronic tools which help the patients and health care centers to manage their information. For instance, the government could implement a web based application where patients could access their information wherever they are located only through internet access. They could find their doctors, medical procedures that they have been through, among other important information needed.

Other study that could be done regarding this topic is the implementation of a digital signature which could help patients to decide what kind of information could be disclosed to health professionals. With this method the patient could decide, for instance, that the doctors secretary only can visualize personal data such as names, address, phone numbers among other non relevant information while providing all necessary health information to doctors and nurses.

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8. Appendices

Appendix A. Questions for Interviews

Health Centers Interviews

Interview to Dr. Santiago García

- How can I obtain copies of my health record?

The patient needs to make a request to the doctor who will subsequently solicit the record to the Medical Direction Department of the hospital.

- Who is responsible for giving patient's health record?

The Medical Direction Department is the responsible for disclosing health records.

- How much does it cost?

It is free.

- How long does the process take?

The process is really fast. Once the Medical Direction Department receive the request the patient will have his record within the next ten or twenty minutes.

- Is it in electronic format or I need hard copies?

The record can be given to the patient in both formats. We use to give the patient a hard copy and a soft copy on a CD.

- What happens if I need my records and I can't find my doctor?

The patient can go the Medical Direction Department by himself and thus solicit the record.

- For how long does the hospital store the record on its database?

The period of time is not strictly defined, but it can go between ten and fifteen years. At this moment the records are stored indefinitely.

- What happens if I move to another city? How can I transfer my health record?

The patient can solicit a copy of the record and take it to another hospital in other city or country.

- Can I access my PHR by phone?

No only physically.

- Do doctors give patients the Notice of Privacy Practice (tell patients how your information is used or disclosed?)

No, the hospital rarely communicate the patient the management that will be given to his information because we assume that the patient already know it.

- When can my health information be shared without my consent?

When the patient can not give consent because of health reasons a direct relative such as children, wife or parents must solicit the record. Also, the information can be disclosed when the National Health Ministry request information for statistics purposes as well as for judicial purposes such as a suing.

- Can the hospital share information with my family without my authorization?

Only when the patient is mentally disabled.

- Do I have the right to see my child's health record?

Only if the patient is underage.

- How can I get another adult's record?

No one can access an adult's health record without consent.

- Where can I locate the federal and state laws that govern the disclosure of my health information?

I think that there is no law related to health records. Maybe the General Health law, but in my opinion you should contact an expert such as Armando Vallejo who is our legal consultant.

- What is the training for people involved in managing my health records?

The training given is to the personnel is a common training for everyone. We teach how to work with the software, the processes for requesting information in the hospital and others common issues.

Interview to Dr. Miguel Molina**- How can I obtain copies of my health record?**

There is no way you can have a copy of your record. If the patient wants information related to his health he must ask the doctor to give him some certification indicating his health conditions.

- Who is responsible for giving patient's health record?

The doctor who worked with the patient must address his request.

- How much does it cost?

The patient should pay the doctor's fee which may vary from a doctor to another.

- How long does the process take?

It depends on the doctor's time. Sometimes it can take several hours and sometimes various days.

- Is it in electronic format or I need hard copies?

The doctor gives a certification letter written in paper.

- What happens if I need my records and I can't find my doctor?

The patient should go to the administration of the hospital and see how could they solve the problem.

- For how long does the hospital store the record on its database?

Records are archived physically indefinitely.

- What happens if I move to another city? How can I transfer my health record?

The patient should ask for a health certification letter to his doctor.

- Can I access my PHR by phone?

No only physically.

- Do doctors give patients the Notice of Privacy Practice (tell patients how your information is used or disclosed?)

No, the doctor does not usually talk with the patient about how his personal information will be treated.

- When can my health information be shared without my consent?

When it is requested by a judge in case of judicial problems or when the Health Ministry requires it.

- Can the hospital share information with my family without my authorization?

No, the hospital can not disclose this information to anyone.

- Do I have the right to see my child's health record?

Yes, if your child is less than 18 years old.

- How can I get another adult's record?

You can not have other person's record.

- Where can I locate the federal and state laws that govern the disclosure of my health information?

I do not know if there is a law that specifies procedures for manipulating health records. Well, maybe the professional secret is regulated by law, but I am not sure.

- What is the training for people involved in managing my health records?

No special training is given to us. We only learn how to write diagnostics on records papers, but no procedures are taught to us.

Interview to Dr. Ramoli Mena

- How can I obtain copies of my health record?

The record can not be given to anyone. What we do is that doctors give patients a certification specifying the diagnostics given and medical procedures the patient has been through in the hospital as well as his clinic history.

- Who is responsible for giving patient's health record?

The certification is given by the doctor in charge of the case.

- How much does it cost?

I do not know the exact amount of money to pay, but I have heard that is a minimal contribution for the hospital. You know that this is a public hospital and patients should pay some money for many of the administrative procedures.

- How long does the process take?

Due to the huge amount of patients that we receive the records are stored physically in archives where the personnel have to look for it. For this reason the process must last weeks and sometimes months depending on the record's age.

- Is it in electronic format or I need hard copies?

The certification is a paper written by the doctor.

- What happens if I need my records and I can't find my doctor?

The patient should go to the Administration Department of the hospital which will try to find the record and will ask one of the doctors member of the hospital to sign the certification.

- For how long does the hospital store the record on its database?

I suppose that decades, but no time is strictly specified.

- What happens if I move to another city? How can I transfer my health record?

You should ask for your certification as you will do it for any other reason.

- Can I access my PHR by phone?

No.

- Do doctors give patients the Notice of Privacy Practice (tell patients how your information is used or disclosed?)

No, most of the time the patient is not interested in knowing how the information will be managed.

- When can my health information be shared without my consent?

When the government request it for judge sentence or any other legal action.

- Can the hospital share information with my family without my authorization?

No. to no one.

- Do I have the right to see my child's health record?

If he is underage.

- How can I get another adult's record?

No one can have access to a patient record.

- Where can I locate the federal and state laws that govern the disclosure of my health information?

Maybe the constitution or the General Health law, but I do not know the law thoroughly.

- What is the training for people involved in managing my health records?

The hospital does not give its personnel specialized training for these purposes.

Attorneys Interviews

Interview to Dr. Daisy Taveras

- Is there any law governing the disclosure of my electronic personal health records? Which institution controls it and in what part of the law can we find it?

We have the General Health Law number 42-01 where we can find in the 155th article which states that the medical centers need to archive all the information about births, deaths and diseases of all patients who attended the hospital.

- Can the hospital share my information without my consent?

No, the hospitals can not give my information to anyone even the patient owner of the information contained in the record can not have the original record. If the patient needs the information the doctor should give him a certification explaining his health situation.

- Who can have access to my health record?

No one can access the record. As I told you even the patient can not have the original record. The record can only be disclosed when ordered by a judge.

- When does the law allow medical entities to disclose protected health information to law enforcement officials?

It can be disclosed through a request made by the public prosecutor, when ordered by a judge or when the National Institute of Forensics Science requires it for legal purposes.

- Is it mandatory to explain the patients the privacy practices with their personal information?

It is not mandatory. The patient does not know what the hospital does with his information.

- Does a digital record have the same legal treatment than a physical one?

Yes, for the privacy protection purposes both type of records are the same.

- Have you had any experience or problem related to health information disclosure or a incorrect record management?

Yes, for example once a lawyer whose client was suing the hospital came to my office and ask me to give him the patient's health record, but I told him that he needs to request it via public ministry in as a legal action.

Other case that I had was that an American patient sent a letter to the hospital requesting the personal health record for health purposes in the U.S. I told him that the health record can not be given to him and referred him to his doctor in the Dominican Republic in order to obtain a certification of his health situation.

- What can I do if I realize that my privacy rights have been violated?

You can sue the hospital or the doctor for damages caused by the illegal disclosure.

- Do you think that it is necessary to create this kind of regulation?

The problem is that the general health law already regulates the disclosure of the information, but a lot of people ignore it.

- If we want to propose a regulation in this regard, what do we have to do and how should we do it?

I should get groups interested in this regulation together and make a law project which needs to be given to a senator in order to be presented to the congress.

- Which institution should be in charge of my regulation?

I think that the Health Ministry should regulate health records.

Interview to Lic. Rafael Armando Vallejo

- Is there any law governing the disclosure of my electronic personal health records? Which institution controls it and in what part of the law can we find it?

No, there is no specific law which regulates the electronic health records. You may find some articles dispersed in the law maybe the General Health Law number 42-01 talks briefly about health records. Also, the Dominican Medical Association Code may have articles related, but the Dominican law lacks of a specific law in this regard.

- Can the hospital share my information without my consent?

No, the hospital can not disclose a patient's information without consent. Only if the patient is not in mental capacity for giving consent or if the patient dies the oldest son or daughter inherits the parent's privacy rights.

- Who can have access to my health record?

The medical personnel can access the record, i.e. doctors, nurses, physicians and others health professionals involved in the process.

- When does the law allow medical entities to disclose protected health information to law enforcement officials?

It should be disclosed when the Health Ministry makes a request for statistics purposes. Also, it should be disclosed when a judge requires the record for legal purposes.

- Is it mandatory to explain the patients the privacy practices with their personal information?

It is not mandatory. In a general sense the patient does not care about what the hospital do with his information. The patient only wants the hospital to solve his health problem.

- Does a digital record have the same legal treatment than a physical one?

Yes, it is the same.

- Have you had any experience or problem related to health information disclosure or a incorrect record management?

Yes, once a German patient died in the hospital and his children asked for the health record. The medical director consulted me and without looking into any law I assumed that the logic thing is that the children inherit the rights for having the record.

- What can I do if I realize that my privacy rights have been violated?

You can sue the hospital or the doctor for damages.

- Do you think that it is necessary to create this kind of regulation?

I think that it is necessary to have a specific regulation especially when we are starting to use electronic personal health records.

- If we want to propose a regulation in this regard, what do we have to do and how should we do it?

First you have to conduct an exhaustive investigation of the whole law in order to find any law which rules electronic health records. If no legislation exists you should create a law project and contact a deputy in order to present the law project to the congress.

- Which institution should be in charge of my regulation?

The Health Ministry and maybe the Dominican Medical Association could support you.

Interview to Lic. Daniel Suarez

- Is there any law governing the disclosure of my electronic personal health records? Which institution controls it and in what part of the law can we find it?

The new constitution of the Dominican Republic in its 44th article proclaims the intimacy and personal honour. This right guarantees the respect and protects the interference in the private life.

- Can the hospital share my information without my consent?

No, the hospital can not disclose your information. It can be disclosed only when the Health Ministry requires it for statistics purposes.

- Who can have access to my health record?

Only the medical personnel which work with the patient can access the record.

- When does the law allow medical entities to disclose protected health information to law enforcement officials?

The medical center have to disclose it when it is ordered by a judge.

- Is it mandatory to explain the patients the privacy practices with their personal information?

It is mandatory to tell the patient what is your information going to be used for and who is going to access it. However, in a general sense it is not applied in medical centers in the DR.

- Does a digital record have the same legal treatment than a physical one?

Yes, it is the same. However, the electronic health record is more vulnerable to security attacks because of transmission mechanisms and other procedures.

- Have you had any experience or problem related to health information disclosure or a incorrect record management?

I can cite an example of this problem. For example, if I use to visit an ophthalmologist and a few months later I decide to visit another one I may ask my old doctor to give me my health records in order to give it to the other doctor. If the first one refuses to give me the health record I can force him, by legal methods, to give me the record.

Another example could be a politician who in order to make campaign for president, ask a medical institution to provide my personal information. This is punished by law.

- What can I do if I realize that my privacy rights have been violated?

You can use the Habeas Data legal mechanism and make the institution to suspend the information they are giving from you. You can also sue the center for damages caused by this disclosure.

- Do you think that it is necessary to create this kind of regulation?

It is extraordinarily necessary a legislation in this regard. Although the Habeas Data is a very useful legal tool it is very general and a more specific regulation is needed.

- If we want to propose a regulation in this regard, what do we have to do and how should we do it?

You may join a multidisciplinary group composed by IT professionals, lawyers and other stakeholders and contact a senator who can propose a law project to the congress.

- Which institution should be in charge of my regulation?

At the present time, courts are in charge of these laws. However, it might be necessary to create a specialized institution which will regulate an electronic health record legislation.

Appendix B. Confidentiality Agreement

In the following confidentiality agreement we omitted names and addresses for confidentiality purposes.

ACUERDO DE CONFIDENCIALIDAD:

ENTRE :

La compañía sociedad comercial organizada de conformidad con las leyes de la República Dominicana, con su asiento social en el Santiago de Los Caballeros, _____, debidamente representada por su Presidente el señor _____, quien es dominicano, mayor de edad, casado, médico, domiciliado y residente en esta ciudad de Santiago de Los Caballeros, con cédula de identidad y electoral número _____, de una parte y quien en lo adelante se denominará por su propio nombre o el de PRIMERA PARTE; y

El DR. _____ dominicano, mayor de edad, _____ médico, domiciliado y residente en esta ciudad de Santiago, con cédula de identidad y electoral número _____ quien en lo adelante y para los fines y consecuencias del presente acto se denominará LA SEGUNDA PARTE.

LAS PARTES ANTES DE PACTAR Y CONVENIR EL PRESENTE CONTRATO EXPONEN LOS SIGUIENTES CONSIDERANDOS QUE SON Y CONSTITUYEN PARTE INTEGRAL DEL MISMO:

CONSIDERANDO: Que la PRIMERA PARTE, es propietaria del HOSPITAL _____, centro de medicina privado que tiene por objeto principal brindar servicios médicos en general, a todos los niveles, ya sean ambulatorios, de emergencia, de internamiento, de consultoría, etc., en el cual está desarrollando la tecnología de almacenamiento de datos con formato digital, de la historia clínica de los pacientes que reciben atenciones médicas en dicho centro de salud, herramienta a la cual tendrán acceso los médicos que desarrollan sus actividades profesionales en cualesquiera de las categorías indicadas en el Reglamento Médico del _____, que son: médico miembro del cuerpo médico profesional; miembro del directorio médico; médico invitado; médico itinerante; médico asistente; médico docente; médico pasante; médico residente; médico pasante de postgrado y médico empleado; así como personal técnico; personal paramédico y personal de apoyo.

CONSIDERANDO: Los datos contenidos en el historial médico de un paciente, se considera como una información íntima, que entra en el concepto de secreto profesional, sujeto a la protección frente al mal uso, por quien es el depositario y guardián de las informaciones, razón por la cual, su uso debe estar rodeado del cuidado, confidencialidad y manejos éticos necesarios, que obliga a la PRIMERA PARTE, a tomar las medidas pertinentes para los fines apuntados.

CONSIDERANDO: A que el artículo 377 del Código Penal Dominicano, trata lo relativo al secreto profesional, al efecto, señala el artículo 377, lo siguiente: Los médicos, cirujanos, y demás oficiales de sanidad, los boticarios, las parteras y todas las demás personas que, en razón de su profesión u oficio, son depositarios de secretos ajenos y que, fuera de los casos en que la ley les obliga a constituirse en denunciadores, revelaren esos secretos, serán castigados con prisión correccional de uno a seis meses y multa de diez a cien pesos.

CONSIDERANDO: Que el Código de Ética Médica del Colegio Médico Dominicano (CMD), contenido en el Decreto #641-05, en su artículo 4 dice lo siguiente: "Constituye un deber para el/la médico el guardar el secreto profesional, un deber que perdura en lo absoluto, aún después de que haya dejado de ejercer sus servicios, exceptuando los casos previstos por disposición de la ley".

CONSIDERANDO: Que las partes entienden conveniente establecer criterios claros respecto al manejo de la información de los datos de los pacientes que se traten en el **HOSPITAL**, y para esos fines han decidido suscribir un **ACUERDO DE CONFIDENCIALIDAD**, que recuja toda la reglamentación del manejo de estas informaciones.

Por lo tanto y en el entendido de que el presente **PREAMBULO** es y forma parte integral del presente acto, las partes **ILAN CONVENIDO Y PACTADO LO SIGUIENTE:**

ARTICULO PRIMERO. OBJETO: Las partes suscriben un acuerdo cuyo objeto es el de mantener como secreto profesional, por tanto bajo el criterio de la confidencialidad, de la **SEGUNDA PARTE**, los datos e informaciones contenidos en el record clínico de pacientes atendidos en las instalaciones de la **PRIMERA PARTE**, y a los cuales tiene acceso en razón de su condición de **MÉDICO** del **HOSPITAL**.

En tal virtud, la **SEGUNDA PARTE** se obliga a:

- No aplicar, ni utilizar, ni revelar, ni difundir, almacenar o transformar los datos contenidos en los records médicos de los pacientes, con una finalidad distinta a aquella por la cual la **SEGUNDA PARTE**, tuvo acceso a la información.
- No comunicar ni permitir el acceso a los datos del paciente, a terceras personas, salvo el personal de apoyo o colaboradores, de los cuales responden, bajo los mismos criterios de confidencialidad de atinentes a la **SEGUNDA PARTE**.

ARTICULO SEGUNDO. DURACION: El presente acuerdo entrará en vigencia a partir de su suscripción y se extiende de manera indefinida, no obstante que haya podido terminar la relación contractual entre las partes en el presente acuerdo.

ARTICULO TERCERO. RESPONSABILIDAD: La **SEGUNDA PARTE**, responderá tanto penal, como civilmente y aún disciplinariamente por la violación personal del presente acuerdo de confidencialidad. Responderá civilmente por cualquier violación causada por sus dependientes o colaboradores al presente acuerdo.

ARTICULO CUARTO. DERECHO AL USO DE LA INFORMACION DIGITAL: La SEGUNDA PARTE, en su calidad de MÉDICO __, tendrá acceso al uso de la información digital, en las condiciones siguientes: A TRAVES DEL SISTEMA FACILITADO POR EL HOSPITAL Y DEL CÓDIGO UNICO DE HISTORIA CLÍNICA DEL PACIENTE FACILITADO POR ESTE ÚLTIMO AL MOMENTO DE LA CONSULTA.

ARTICULO QUINTO. SOLUCION DE CONFLICTOS: En caso de disputas relacionada con este contrato, no resueltas amigablemente, ambas partes acuerdan someter el diferendo a la conciliación y arbitraje de la Cámara de Comercio y Producción de Santiago Inc, por lo que otorgan competencia exclusiva a dicha institución para conocer y decidir respecto del o de los puntos en litigio.

HECHO Y FIRMADO en tantos originales como partes intervinientes, una para cada una de las partes, en la ciudad de Santiago de Los Caballeros, Municipio y Provincia de Santiago, República Dominicana, a los VEINTIUNO (21) días del mes de OCTUBRE del año dos mil nueve (2009).

Por LA PRIMERA PARTE

DR.

PRESIDENTE

Por LA SEGUNDA PARTE

DR. _____

Yo, _____, Notario Público de los del Número del Municipio de Santiago, con matrícula del Colegio Dominicano de Notarios número novecientos cuarenta (940), CERTIFICO que las firmas que anteceden han sido

puestas voluntariamente en mi presencia por los señores DR.


y DR. __ de generales y calidades que constan en el acto precedente y personas a quienes doy fe conocer. En la ciudad de Santiago de Los Caballeros, Municipio y Provincia de Santiago, República Dominicana, a los VEINTIUNO (21) días del mes de OCTUBRE del año dos mil nueve (2009).

LIC. _____

NOTARIO PÚBLICO

Appendix C. Physical Personal Health Record

This is a sample of how health records are managed physically in medical centers.



CLINICA COROMINAS, C. por A.

Restauración No. 57 * Tel: (809) 580-1171
Santiago, Rep. Dominicana

Caso No. _____

Nombre: _____										Edad: _____																			
Diagnóstico: _____																													
Médico: _____										Enfermera: _____										Privado No. _____									
Fecha																													
Días Hosp.																													
Días Opera.																													
R P T	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT	MT										
38 160 41																													
93 140 40																													
28 120 39																													
23 100 38																													
18 80 37																													
13 60 36																													
8 40 35																													
Pulsación																													
Respiración																													
Orina (Muc)																													
Excretación																													
Presión Arterial					Tiempo Coag.								Tiempo Sang.																
Aha.																													
Operación Hecha																													



CLINICA COROMINAS, C. POR A.

Restauración # 57 • Tel.: (809)580-1171
Santiago, Rep. Dominicana

HOJA DE ENFERMERIA

NOMBRE: _____

MEDICO: DR. JATON HABITACION # 103[illegible]



CLINICA COROMINAS, C. por A.

Restauración No. 57 • Tel.: (809) 580-1171
Santiago, Rep. Dominicana

HOJA DE SIGNOS VITALES

NOMBRE: _____ EDAD _____ HABITACION # _____

MEDICO: _____ DIAGNOSTICO _____

[illegible]



CLINICA COROMINAS, C. por A.

Restauración No. 57 * Tel: (809) 580-1171
Santiago, Rep. Dominicana.

EVOLUCION DIARIA DEL ENFERMO

NOMBRE: _____

MEDICO: _____ HABITACION # _____

[illegible]



A CLINICA, COROMINAS, C. por A

Restauración No. 57 • Tel: (809) 580-1171

Santiago, Rep. Dominicana.

ORDENES MEDICAS



NOMBRE: _____

MEDICO: _____ HABITACION # _____

ORDEN

[illegible]